



# Helping Hands

**Palliative Care** is comprehensive, interdisciplinary care of seriously ill patients and their families, which focuses on comfort, support and the relief of suffering.

## Welcome

It is the moment when death may be near which most rivets our attention. In a hospital, many of those moments take place in the Intensive Care Unit (ICU). For both physicians and patients, the ICU is the crucible, the place where the most critical decisions are made and where the consequences of those decisions are greatest. That is exactly why, for those of us who seek to extend the benefits of Palliative Care to all patients, no area of medicine is more important to address than Intensive Care.

Many of the critical decisions made in the ICU have to do with advanced science and technology: medications that are only used in the ICU, mechanical ventilators to sustain breathing and a host of other equipment and interventions sometimes described as capable of "artificially prolonging life."

Patients are often incapable of communication or decision-making when in the ICU, and families and physicians must define the goals of care together. This difficult process includes understanding the emphasis each patient has placed on their quality of life and determining whether they would want the aggressive treatment that is the traditional purpose of the ICU. It also includes finding a way to skillfully address patient and family suffering and provide comfort and dignity to patients and loved ones even when concurrently pursuing recovery and cure.

As the articles in this issue of Helping Hands describe, the ICU offers an unparalleled challenge and an opportunity for the development of Palliative Intensive Care.

**Stuart Green, MSW, MA**  
Editor, Helping Hands

## ‘Doing Everything’: Palliative Care in the ICU

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*“I want you to do everything.”*

As physicians, we often hear this phrase spoken by family members when asked to participate in the healthcare decision-making of a patient who recently suffered a health crisis significant enough to need transfer to the Intensive Care Unit (ICU).

*Everything* in the ICU often means just that: catheters (peripheral venous, central venous, PICC, arterial, and urinary), tubes (endotracheal, nasogastric, orogastric and rectal), continuous telemetry, external pacemaker, temporary transvenous pacemaker, continuous pulse oximetry, oxygen (by nasal cannula, cool mist mask, non-rebreather mask, CPAP, BiPAP), mechanical ventilation (assist control, pressure control, PEEP), peritoneal dialysis, hemodialysis, neuromuscular blocking agents, vasopressors (single, double, triple), inotropes, broad spectrum antibiotics, anti-sepsis agents, blood products (PRBC’s, platelets,

cryoprecipitate, fresh frozen plasma), hourly vital signs, daily x-rays, daily blood tests, tube feeds, total parenteral nutrition, sedation, pain control, DVT prophylaxis, GI bleed prophylaxis, tight glycemic control, universal precautions, contact isolation, respiratory isolation, negative pressure rooms, strict handwashing, and — if needed for patient safety — physical restraints.

And doing everything requires *everybody*: nurses (RN, LPN), clinical coordinators, nurse educators, unit representatives, social workers, discharge planners, utilization reviewers, therapists (respiratory, physical, occupational, speech/swallow), dietitians, nutritionists, interns, residents, clergy, technicians (echocardiographic, bronchoscopic, endoscopic, PICC, radiologic, electroencephalographic, biomedical and environmental), pain/sedation team, nurse practitioners, physician assistants and physicians. On occasion, we need to get others involved: lawyers, risk managers, committees (e.g., Bioethics), state guardians and the court system.

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# Helping Hands

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Palliative Care Program  
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## 'Doing Everything' continued from page 1

**In 2004, 'doing everything' in the ICU requires yet one more thing — palliative care.** Historically, palliative care was a last offering in the ICU, with attention to alleviation of pain and suffering at a time when "standard care" was no longer resulting in a return to function, or cure. In the past, aggressive care with the goal of cure was offered first. If care did not result in a positive outcome, the goal of care changed, with attention then directed at comfort. As clinicians looked more deeply into the issues of pain and suffering in the ICU, myriad causes were found, with many of these inadequately addressed by the historic standards of care.

**Patients in the ICU can have pain and suffering from a variety of sources.** For patients who have had surgery, for example, post-operative pain at the incision site is an obvious source. In the past, pain medication was given when requested by a patient, and there was no follow-up assessment on a regular basis. If the patient had recurrent pain, then additional pain medications could be given, as long as the dose and frequency were within the orders as previously written by the physician. If the patient had pain uncontrolled by the medications as ordered, a nurse might take the initiative to call the physician for an adjustment of the dose, frequency or medication itself in order to alleviate the patient's pain.

This has changed, and pain is now much more actively addressed. All nurses are specifically trained to assess both pain and sedation before starting their clinical work, and recertified on an annual basis. Currently, pain is assessed every two hours in the ICU as the fifth vital sign. Pain scales are used as part of that assessment and if a dose of pain medication is used, then the patient is reassessed in

15 minutes if the medication was given intravenously, or in 60 minutes if the pain medication was given orally or subcutaneously.

Pain from organ ischemia or infarction (including myocardial infarction, treated in the Coronary Care Unit) is also quite common. Ischemic pain or pain from infarction is treated like other types of pain, with morphine sulfate being the traditional agent used. However, there is an emphasis with pain management in the setting of a myocardial infarction to reestablish coronary blood flow with coronary vasodilators (such as nitroglycerin), thrombolytic agents (such as tissue plasminogen activator) or interventional reperfusion techniques (such as angioplasty or bypass surgery). In addition, supplemental oxygen is administered to improve oxygen delivery to the ischemic cardiac muscle, which should also serve to alleviate pain.

Patients also have pain at the sites of the various tubes and catheters, as well as arterial and intravenous lines that invade their bodies, including the pain from daily blood tests. And no matter what we're told, daily blood tests do hurt.

Pain can occur from simply laying in one position for too long, and the technology of "rotating beds" or kinetic therapy has been found to be useful in both addressing that pain and in helping to prevent the development of decubitus ulcers (bedsores). Doctors and nurses in the ICU have a lower threshold for utilizing a rotating bed when we identify a patient at risk for long-term immobility. The Wound Care Service is called at the first sign of a problem, based upon the physical examination findings of the doctors and nurses caring for the patient.

And pain can occur from irritation of the vein as medications are infused. If a patient has sensitive veins, we might be more apt to place a PICC line (percutaneously inserted central catheter), which delivers the medications into a large central vein in the chest, avoiding the sensitivity and thus the discomfort that a patient would feel in a small, peripheral vein.

**Thirst, hunger, feeling too hot or too cold or simply having an itch that cannot be scratched are all sources of discomfort for the ICU patient.** If a patient expresses that they are cold, we place heated blankets on them. If they are hot, we can have a fan blowing on them.

Another source of discomfort is the loss of external environmental cues for the ICU patient. This leads to disruption of the relationship between the day/night cycle and the sleep/wake cycle, with some patients consequently developing ICU psychosis and “sundowning.” We try to allow as much ambient light as possible into a patient’s room, in order to allow natural day/night cues to continue. At times, we can also turn a patient’s bed or chair to allow them to actually look out of the window.

To deal with light pollution (too much bright light), and noise pollution (constant alarms), the ICU has adopted a period of “quiet time,” from 2–4 pm, where the lights are turned down and every effort is made to allow what essentially amounts to a nap for the patient. Patients are awakened only as the clinical need arises.

But the ICU patient’s sleep is still commonly disrupted because of the need to monitor vital signs and do examinations. Pungent odors, nausea, dizziness and confusion (from either the medical conditions themselves or from unwanted side effects from med-

ications) are other sources of discomfort. These conditions, along with light pollution and noise pollution can turn any recipient of care into what I would call a victim of care.

**Fear and anxiety are also large contributors to patient suffering**

In the past, pain medication was given when requested by a patient, and there was no follow-up assessment on a regular basis.

**in the ICU.** Patients worry about issues from their non-patient lives: family matters (“who will take care of my kids or my spouse if I’m laid up in the hospital”), financial matters, business, housing and legal issues, just to name a few. And then there is anxiety about the illness itself: is it life threatening? Will I make it home alive? Will I become an invalid? The availability of social work consultation for ICU patients and families is one way these concerns are addressed.

**One common source of suffering for the ICU patient is the use of mechanical ventilation, a common ICU intervention.** Pain or discomfort is almost universally associated with the presence of an endotracheal tube that connects a patient to a mechanical ventilator. The discomfort is so great that almost no patient can be supported by a mechanical ventilator without continuous sedation.

Ventilators are used to deal with dyspnea, or shortness of breath. When

severe, dyspnea is one of the most distressing of symptoms. As patients with respiratory failure are admitted to the ICU, the presence of severe dyspnea commonly causes them to become wildly agitated, often requiring several staff members to physically hold them down as sedation begins to take effect and the endotracheal tube is inserted. The need for sedation continues for the duration of the time these patients spend on the mechanical ventilator. If the patient is not sedated adequately, then the timing of the patient’s respirations will not be in rhythm with the timing of the breaths provided by the mechanical ventilator, a condition called patient–ventilator asynchrony.

**Imagine trying to exhale while a machine is trying to blow a breath into you at exactly the same time.**

This asynchrony can potentially result in barotrauma, a life-threatening condition that often results in a collapsed lung. In addition, as sedated patients are awakened, they also experience disorientation and may become as agitated as when they first came to the ICU in respiratory failure. Making matters worse, the ventilated patient who requires continuous sedation is unable to communicate.

The sedation required to prevent patient–ventilator asynchrony also prevents patients from communicating. In the past, as larger and larger doses of sedatives were used, and as sedatives with a longer duration of action were used, patients would often require many days to wake up after sedation was discontinued. This came at a great economic as well as physical cost in that patients who were medically ready to be weaned from mechanical ventilation could not be because of the prolonged sedation.

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# ‘Intensive Care’ of Patients and Families:

## Palliative Care in the ICU

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When a patient is admitted to a hospital Intensive Care Unit (ICU), that patient and his or her family is suddenly thrust into a high-tech, intense medical setting that has been designed and constructed to fight illness and injury and to prolong life by all possible means. Multiple specialists in care of the critically ill, and multiple monitoring devices, life-support machines, tubes and intravenous lines create an intimidating atmosphere, more so than in any other area of the hospital. For the families of these critically ill patients, there is an overwhelming amount of technical and medical information to take in and integrate into an understandable picture of what is happening to their loved one.

Many of the patients who enter the ICU environment were previously living independently, in a relatively healthy state and range in age from young adults to the very old. When a catastrophic event lands a family member in the ICU, whether it is from a stroke, heart attack, head trauma, overwhelming infection or organ failure, families are ill-prepared to navigate the stormy waters of deciphering what is happening, what lies ahead and what are the best choices among a myriad of treatment options. It is analogous to being in the middle of a symphony orchestra, having no familiarity with classical music, and trying to discern which musical instruments are making which sounds and how each sound contributes to the harmony of the whole.

Choosing treatments most appropriate for a patient is complicated because it requires taking into account the clinical condition of the patient, the availability of a wide range of life-prolonging interventions, not all of which will be effective for a particular person’s condition or situation, the possibility of recovery, the burdens of treatments, the potential benefits and, most importantly, the wishes of the patient if expressed or if known by the family. It is this myriad of considerations that often sends families into a tailspin. The stress and sometimes

ICU care is defined by nationally recognized criteria as the most acute level of care in a hospital.

conflicts among family members complicate reasoned decisions. Families not only find themselves suddenly involved in the unfamiliar world of the ICU, but are simultaneously trying to balance responsibilities at work, the care of children or others at home, financial needs and disrupted family plans.

Every medical event or critical turn for the worse requires new decisions.

Should a ventilator be used to support the lungs when breathing has failed? Should a feeding tube be surgically implanted to provide nutrition after a devastating stroke? Should dialysis be started when the kidneys fail? Should a tracheostomy be performed to allow for long-term ventilator support? Should cardiopulmonary resuscitation (CPR) be performed if the heart stops beating? Should powerful antibiotics be used to treat infection when the patient is unlikely to recover? Should blood pressure medications continue to be given when the pressure continues to fall? When a patient cannot communicate and participate in treatment decisions, the family must make these profound decisions on the patient’s behalf.

In addition to all of these difficult questions, daily review of the patient’s needs by the medical team drive the level of care decisions. ICU care is defined by nationally recognized criteria as the most acute level of care in a hospital. There are many other levels of care in the hospital setting such as step-down units, medical units, surgical units, and so on. The goal of care in all of these hospital environments is to stabilize and transfer the patient to a less acute level of care to improve outcomes for the patient and the family. Families often have difficulty in understanding this dynamic process and feel anxious about the change in levels of care. This is particularly true in the transfer of patients out of the ICU setting. Families have developed a comfort level with the intensity of care and staffing required in an ICU and fear that their loved

one will not receive adequate care in another setting. These decisions about level of care are made by the patient's physician based upon medical diagnosis and the patient's clinical needs.

The difficulty of participating in and making these decisions contributes to the immense emotional, psychological and spiritual burdens carried by the families of patients in the ICU. These family burdens are the focus of palliative care. Palliative care is a comprehensive interdisciplinary approach to the suffering of seriously ill patients and their families. While palliative care is especially needed when patients are dying, it should also be provided to all seriously ill patients, even while curative efforts are underway. In the ICU, as in other medical settings, it is often difficult to predict who will live and who will die, and when. While the ICU is best known as a place for the high-tech battle to preserve and prolong life, about 20% of all patients do not survive their ICU stay.

Suffering for patients and their families starts immediately and intensifies as the reality of a serious illness manifests itself. The "loss" of the patient in his or her former capacity, the fear of dying, anger, anxiety, sadness, loneliness and the search for meaning in the life and potential death of a loved one all contribute to the emotional roller coaster ride for patients and families in an ICU setting. Cultural and religious beliefs and traditions function as important supports for patients and families during the time spent in an ICU but are often unintentionally minimized by the high-tech, clinically oriented surroundings.

How can a palliative care approach help to support these patients and families during this time of crisis? Palliative care, as described above, does not preclude the simultaneous provision of life-sustaining, curative treatments when appropriate, aimed at recovery or prolongation of life. Palliative care simply addresses the

concurrent needs of patients and families, regardless of prognosis, for relief of suffering, which includes physical, emotional, psychological and spiritual.

Whether on the way to recovery or beginning a process of dying, the "person in the patient" is the focus of a palliative care approach. Who is the person in the ICU bed? What are his or her values, wishes and beliefs? How

Whether on the way to recovery or beginning a process of dying, the "person in the patient" is the focus of a palliative care approach.

can we support the family to achieve those ends for the patient? How can we support the family in their difficult journey?

Often, fragmented communications or lack of complete explanations about medical conditions and prognosis lead to increased anxiety and stress for the family members. Putting together the medical pieces such as cardiac status, brain status, lung status and the total picture of clinical diagnosis and prognosis can help families clearly focus on the decisions to be made when emotional stress is high. Patients and families need to completely understand the decisions to be made, the burdens and benefits of each option available, and the ultimate impact of those decisions on the patient and family. A palliative care team gathers and organizes information for the family and helps them

understand the information, serving as a link between a variety of medical professionals and the family. This helps families focus on decisions that need to be made at a time when emotions and stresses make such judgments difficult. Facilitating consistent and supportive communication between professional caregivers and families is a key component of palliative care in the ICU.

When patients are able to understand and communicate, all efforts should be made to include them in honest dialogue about their illness, the prognosis, the options for treatments and the burdens and benefits of such treatments. Withholding information from patients to protect them from "giving up hope" is often a family's first emotional response. It is important to help families understand that given honest and accurate information about their condition, most patients have the ability and emotional strength to make important decisions and to accept and cope with their illness.

Withholding information from patients for fear of creating hopelessness most often isolates the patient, preventing them from discussing their thoughts about dying and increasing their fears. St. Thomas Aquinas offers a useful perspective on hope. Since none of us can ultimately avoid death, we cannot hope never to die. Hope, then, for dying patients, can reach beyond the mortal limits of life and include spiritual and religious beliefs, hope for memories and spiritual connections to remain with those we love, and other deeper and more meaningful desires than the hope for cure of a terminal illness. Patients have a right to participate in their medical treatment choices if they can. To do so, they need complete information about their conditions and the support and encouragement to openly

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## ‘Intensive Care’ *continued from page 5*

communicate with family members and caregivers about their desires.

From the first day of admission to an ICU, the patient and family members (as authorized by the patient) should be given total, accurate and complete information about all aspects of the diagnosis, prognosis and treatment options. Being prepared for what may occur and being involved in the daily decisions of care can facilitate comfort and decrease anxiety about potential

outcomes. Being supported emotionally, psychologically and spiritually along the way can make the road less difficult.

When curative treatments are no longer deemed beneficial to the patient and palliative care becomes the primary and singular focus for the patient, much can be done to care for the patient outside the realm of aggressive high-tech life supports. Transfer of the patient to an appro-

priate setting can promote that change in focus. Families often need encouragement to remember those things that matter most to dying patients. Reading favorite poetry, listening to music, sharing memories, massaging of feet and hands, and other creative activities centered on the patient can improve the quality of life remaining for any patient and help support the family in their bereavement.

## ‘Doing Everything’ *continued from page 3*

Over time, continuous drips of short acting sedatives have become the standard, so that patients can be rapidly awakened and rapidly removed from mechanical ventilation when improvement in their condition warrants. Continuous drips of short acting sedatives (Propofol) allow sedation to be turned off briefly on a daily basis in order to perform neurologic assessment of an awakened patient. In addition, these short-acting sedatives allow more rapid weaning from mechanical ventilation. Finally, there is the option of calling the Pain Service to assist with the management of pain and sedation in the ICU, an option that did not exist just a few years ago.

In 2004, what was once offered as comfort care when all else had failed is now part of the “everything” we should offer patients and families at the time that they enter the ICU and provide in conjunction with the other ICU therapies. **The most important of the key elements of palliative care in the ICU — or in any medical setting — is the need for direct and ongoing communication between**

**the healthcare team and the patient “team”: the patient, family members, significant others and healthcare proxies.**

In the ICU, discussion of the risks and benefits of treatments and the alternatives can be very complicated. In addition, because ICU patient care is a very dynamic process, changing quickly, the palliative care discussion needs to be an ongoing one, not simply an informed consent discussion prior to a procedure. The ratio of standard care to palliative care may be in constant flux in the ICU, depending not only on the changing pathophysiological status of the patient, but also on the changing emotional and spiritual needs of the patient.

Recent national medical and lay literature has focused attention on the need for palliative care in the ICU. Potential benefits of this new focus are improved patient, family and staff satisfaction; reduction of critical care utilization with no change in overall mortality; and institutional cost sav-

ings. Intensive communication of goals and outcomes between physicians and family members results in earlier access to palliative care.

Historically, in our efforts to ‘do everything’, we have focused on the disease, our technology and the data. Medical training emphasized medical history taking, the physical examination, and test ordering and data interpretation. But the patient sometimes got lost in that formula. An emphasis on palliative care reorients us to the patient. It emphasizes patient preferences and choices, encourages patients to help determine the course of their own care and encourages those of us in Critical Care to improve our communication with patients and families. It is now time for palliative care in the ICU to become part of ‘doing everything.’

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A palliative care approach in the ICU setting is imperative if we are going to provide humanistic, compassionate medical care to seriously ill patients and their families. This multi-disciplinary approach to the patient and family includes physicians, nurses, social workers, chaplains, and other consultants as may be dictated by the needs of the family and the patient. ICU care is geared to save lives and promote healing and palliative care is

critical to the transition to ultimate recovery. However, not all patients are among those who recover. We therefore must approach each patient and family with the same supports to prepare them for whatever the outcome may be and to provide them with consistent communications on a regular basis along the way. Only through this 'person-focused' palliative care approach can we assure the total compassionate care of each patient and

family who enters the world of the ICU.

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## Bioethics Consultation in the ICU

Jeanne Kerwin, MMH, MICU, Bioethics and Palliative Care Coordinator, Overlook Hospital

Regina was an 89-year-old retired college professor who never married, lived alone and was very active in local politics and her community. She drove her car around town and occasionally kept in touch by telephone with her niece, who was her only living relative.

Regina had a history of not going to the doctor and expressing her aversion to hospitals. She preferred to drink herbal teas and manage her own health care. Last week, however, Regina collapsed in her home and was able to call 911 for help. She was admitted to the hospital with a serious GI bleed, unable to communicate upon her arrival in the Emergency Department. Regina suffered a cardiac arrest in the Emergency Department and was resuscitated and put on a ventilator to help her breathe. After being transferred to the Intensive Care Unit (ICU), Regina remained on the ventilator. Further tests revealed she had metastatic cancer with a large obstructing tumor in her bowel. She remained unresponsive and ventilator-

dependent for several days before her niece was located and contacted.

Regina's niece was very fond of her aunt and came from New York State to see her in the hospital. Upon listening to the doctors about her aunt's condition and extremely poor prognosis, her niece felt strongly that her aunt would not want to be maintained on machines if there was no hope of her recovering to a condition in which she could live independently and do the things she loved to do. However, she was very uncomfortable being the one to make such profound decisions for her aunt. Regina had never discussed health care choices, nor had she documented her wishes in a Living Will. Her niece wondered, "How can I make such important life and death decisions based upon my feelings? What legal responsibilities do I have?"

A bioethics consult team was called in to meet with Regina's niece. They presented the clinical information about Regina's present condition and the prognosis for recovery. There was little or no hope of Regina ever regaining

consciousness. In addition, she had a serious underlying disease that was not reversible and would require surgery in order to keep her comfortable.

Regina's niece was asked to tell what she knew about her aunt and her life. The goals of care were discussed, with the suggestion that a palliative care plan be considered, with comfort as the focus instead of curative treatments and artificial life supports. Regina's niece felt strongly that her aunt would want a dignified and comfortable death rather than a prolonged existence in the ICU.

The consult team assured her that her knowledge of her aunt's life and values was important and could be used to make a "substituted judgment" for her aunt about what was the appropriate care plan. In terms of clinical judgment, a palliative care approach was appropriate because her disease could not be cured and her present condition could not be reversed. Medicine could only offer artificial prolongation of life.

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## Bioethics Consultation

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In terms of what was in the best interest of Regina, a palliative care approach seemed to fit her lifetime values as known to her niece.

Consensus was reached between Regina's niece and her doctor. She was removed from artificial life supports, made comfortable with medications and died peacefully within a few hours.

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## Contributions

The Overlook Hospital Palliative Care Program coordinates and provides numerous services to our patients and community, including bioethics and palliative care consultations, services for family caregivers and palliative care education for health care professionals, clergy and communities.

The mission of Helping Hands, Overlook Hospital's Palliative Care Program Newsletter is to provide the communities we serve with information that helps patients and families be more knowledgeable participants in their care and to advocate for the integration of palliative care

approaches into all areas of health care. In particular, we hope to increase community awareness of the importance of palliative care.

If you are interested in supporting our work with a contribution, please send a check to "Palliative Care Program, Overlook Hospital Foundation," 36 Upper Overlook Road, P.O. Box 220, Summit NJ 07902-0220, or contact Dr. John Gregory, Palliative Care Program Director, at (908) 522-5339 or [john.gregory@ahsys.org](mailto:john.gregory@ahsys.org).



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*Helping Hands*

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Palliative Care Program